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Using a booklet to deliver information in patients with dysphagia – the impact on satisfaction with communication, knowledge and emotional state

Dissertação submetida para obtenção do grau de Mestre em Comunicação

Clínica Faculdade de Medicina da Universidade do Porto

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AGRADECIMENTOS

"Ninguém escapa ao sonho de voar, de ultrapassar os limites do espaço onde nasceu, de ver novos lugares e novas gentes. Mas saber ver em cada coisa, em cada pessoa, aquele algo que a define como especial, um objeto singular, um amigo,- é fundamental. Navegar é preciso, reconhecer o valor das coisas e das pessoas, é mais preciso ainda."

Antoine de Saint-Exupery

A Deus, por me mostrar o caminho e torná-lo sempre bonito.

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Declaração de dissertação de mestrado

De acordo com o art.3 do capítulo “Tarefas a realizar” do regulamento do Mestrado em Comunicação Clínica, a presente dissertação consta da realização de dois artigos de investigação:

ARTIGO DE INVESTIGAÇÃO I

"Eat well and live better" - Development and validation of a personalized instruction manual for home feeding in patients with neurological dysphagia

ARTIGO DE INVESTIGAÇÃO II

Information at discharge in patients with neurological dysphagia - impact on satisfaction with communication, happiness and information about the swallowing disorder

O conjunto dos dois artigos de investigação submetidos para publicação científica constituirá a presente dissertação para obtenção do Grau de Mestre.

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ARTIGO DE INVESTIGAÇÃO I

"Eat well and live better" - Development and validation of a personalized instruction manual for home feeding in patients with dysphagia

Article submitted to the journal "Dysphagia"

Title

"Eat well and live better" - Development and validation of a personalized instruction manual for home feeding in patients with neurological dysphagia

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Abstract

Dysphagia can be a serious health threat due to the risk of aspiration pneumonia and other complications responsible for increasing the number of hospital admissions. Health professionals need to prepare patients and family members to make changes in dietary procedures after discharge to prevent complications. The use of booklets was considered particularly effective in this effort, especially when used in a personalized way. This study describes the development and validation of a booklet to provide to patients with dysphagia at the time of hospital discharge.

The manual was developed based on a literature review, open questions to a panel of ten experts and a focus group with seven patients and caregivers. The final version of the manual was submitted to validation to a group of 23 experts, and 22 patients and caregivers. The questionnaire applied addressed the purpose and content, structure and presentation of the manual, readability and relevance, using a Likert scale of 0 to 4. A score equal to or greater than three was considered suitable for validation. All the 19 questions obtained a score equal to or above three in all the items of the validation questionnaire showing a good acceptance by experts and the target population.The manual, developed with an accessible and simple language appears to be a useful resource to be used in clinical practice.

Keywords

Health communication; Booklet; Dysphagia;

Introduction

Patients with dysphagia present difficulty in swallowing solid foods and/or liquids, which may result from neuromuscular disorder or mechanical obstruction [1].

Swallowing is a coordinated process divided in two voluntary (preparatory and oral phase) and two involuntary stages (pharyngeal and esophageal phase) [1]. Various neurological causes may impair the nervous control of the musculature involved in swallowing, namely stroke, head trauma, dementias and neurodegenerative diseases, such as motor neuron diseases, amyotrophic lateral sclerosis, multiple sclerosis, ataxias and others [2]. Dysphagia affects more than 50% of survivors of stroke, 52% to 82% in Parkinson's disease, 40% of patients with myasthenia gravis, 44% of patients with multiple sclerosis, 40% of patients with other dementias and is the initial symptom in amyotrophic lateral sclerosis in 60% of cases [4-6]. Recovery can occur in the majority of post stroke patents, but in other neurological disorders swallowing impairments tends to persist [5, 6].

The complications of dysphagia are divided into those that may affect patient safety at respiratory level and nutritional complications affecting the efficacy of the swallowing process [7]. Respiratory complications are complex and cyclical, and have repercussions on health status, morbidity and mortality, as well as on patients' quality of life [5-7]. Malnutrition on the other hand leads to impaired immunity, and due to loss of muscle mass may be a cause of increased mortality. Dehydration is another consequence of oropharyngeal dysphagia that may endanger the patient's safety, through immune dysfunction, infections and serious skin lesions [5-7].

Dysphagia treatment - Dietary modifications

To obviate these consequences and complications patients with dysphagia are usually submitted to rehabilitation and dietary modification. Food adaptations are made according to the degree of dysphagia and the sensorimotor skills of the patient and can be associated to training in swallowing techniques [4].

General dysphagia therapy programmes include dietary texture modifications and/or alteration of fluid viscosity to minimize the risk of laryngotracheal aspiration and increase comfort at mealtime [4, 8].

Inconsistency in dietary recommendations and procedures can lead to serious clinical complications such as pneumonia, asphyxia and even lead to death [9].

Booklets: their use in health communication

Information regarding food and beverages adaptation and comfort at meal time must be provided to patients and caregivers at the time of hospital discharge. Health professionals – nurses, doctors and speech and language pathologists, hare expected to deliver clear, tailored and objective information to optimise adaptation and prevent dysphagia complications [4, 10].

In previous studies this information provision is described by the patients as insufficient and generalized, with some authors indicating a patient´s preference for more complete, simple and individualized information. Completing verbal communication, the use of written information was considered particularly effective in this effort, especially when used in a personalized way. Clear and simple language, schemes, images and an adequate font have proved to facilitate the understanding of information [11-13]. The use of a booklet with clinical information has already been described as advantageous in areas such as implementation of cardiac pacemakers, discharge after surgery in urology and other surgical procedures that require complex instructions after discharge [14, 15]. For example, using a booklet at discharge after vascular surgery showed significant improvements in patient self-care and fewer complications compared with the control group [14]. The professionals considered the use of this tool as advantageous in helping their patients, with significant impact on self-management and less concern about their health status [11-14].

In patients with dysphagia to guarantee variability and safety in food, it is necessary to explain the changes in the consistency of foods, which industrialized products can help and how to prepare meals [13]. To the best of our knowledge no studies have been performed to demonstrate the clinical utility of a written manual in patients with neurological dysphagia.

We aimed to develop and validate a booklet in European Portuguese to provide to patients with dysphagia and care givers at the time of hospital discharge, with the purpose of providing clear, specific and individualized dietary instructions to this population.

Methods

The manual was developed in three phases: 1. review of the literature, 2. preparation of the manual 3. validation of the manual. The preparation phase included the selection of material - information, images, diagrams, manual organization, the contributions of a panel of experts in clinical communication and speech therapy, and the suggestions of a group of patients with dysphagia and their caregivers.

Review of the literature

Articles published from January 2014 to January 2018 where searched in the Pubmed database, with the keywords "dysphagia" OR "swallowing difficulties" AND "sign and symptoms", "Food thickeners", "Health booklets". From the 83 articles retrieved with the keywords "dysphagia" OR "swallowing difficulties" AND "sign and symptoms", 79 were excluded after reading the titles and abstracts. Four articles were used in the preparation of the booklet and the selected information was adapted and translated for this purpose [17-20]. With the keyword "Food thickeners" nine articles were found and analysed [21-29] and with the keyword "Health booklets" 707 articles were found and 17 were selected for reading, analysis and to assist in the construction of the manual [31- 46].
With the literature search no dysphagia booklets or articles published in this area were found.

Preparation of the booklet

The selected publications were subjected to a reflexive analysis, aiming the construction of a manual with relevant and accessible information. Theoretical information on the definition of dysphagia, possible aetiology of the symptom and consequences was adapted and translated. A customizable section was built on how to prepare food and how to use thickeners. Practical information regarding correct posture during meals, warning signs of possible complications was also included. The schemes and illustrations selected to integrate the manual were designed with the Adobe Illustrator program, by a professional designer under supervision of the authors, as well as the formatting and configuration of the pages. The initial marquee was presented to a group of clinicians with expertise in clinical communication and to a group of speech and language therapist experienced in treating dysphagia (n=10). The selection of professionals followed a convenience snowball approach and all the invited experts who agreed to participate

received a copy of the booklet draft by email. A questionnaire including four open question's “What do you think about the information contained in the manual”, “What would you add in the manual or would you withdraw to the information content?” “Give us your opinion about the pictures, colours and typeface of the manual” and “What changes would you make in the manual?” was emailed via the Google Forms questionnaire platform, maintaining the anonymity of the responses. Of the panel of experts 20% were male and 80% are female. As for literacy, 20% completed doctorate, 70% master's degree and 10% undergraduate degree. A summary of the responses to the questionnaire are showed in Table 1.

Table 1. Summary of comments from the panel of experts (n=10)

	Positive Aspects	Aspects to Improve
Content	Clear information;	Include the information: poor water intake causes dehydration and respiratory complications can lead to death; Add examples of foods for each consistency; Highlight the «Eat Slow!»; Add how administer the meal; Include that we are all responsible for the success of rehabilitation, and that there is a solution: rehabilitation.
Language	Simple language;	Explain terms such as well-seated and normal swallowing;
Organization	Well structured;	Change the order of the tips to improve the meal;
Layout and typography	Good font size;	No suggestions;
Illustrations	Colourful;	Include photos of people with various ages;

Information was also collected from the target population (n=7). Following the suggested a focus group was organized integrating patients with dysphagia and their caregivers. The three stages were followed in the accomplishment of a focal group: Stage 1 - Elaboration of the script, election of a mediator and selection of participants considering the target audience of the study; Step 2 - Conduct the meeting with audio recording; Step 3 - Analysis of the opinions of the different participants. Focus groups do not use probability

or random samples, and in the present study a convenience sample was selected. Number of participants and of open issues to promote discussion were established according to the literature [47, 48]. Patients (n = 3) and caregivers (n = 4) were invited to participate after an oral explanation of the objectives and requested consent for audio recording (Appendix 1). Forty three percent of the participants, were males and 57.14% were females. As for educational qualifications, 28.6% attended higher education. The meeting was held for 30 minutes in a room previously reserved following the pre-prepared script with five open themes, and was mediated by one of the authors (Appendix 2). The patients and caregivers responses are showed in Table 2.

Table 2. Summary of comments from the focus group (n=7)

	Positive Aspects	Aspects to Improve
Content	Clear information;	Suggestions of meals; How to prepare the diets;
Language	Simple language;	No suggestions;
Organization	Well structured;	No suggestions;
Layout and typography	Adequate font size;	No suggestions;
Illustrations	Adequate and simple;	More images of adapted meals;

Validation

The final version of the manual was submitted to validation by a different group of experts (n=23) and of patients and caregivers (n=22). The process was completed through a questionnaire developed for each group (Appendix 3). Questions included referred to the purpose, contents, structure, graphic presentation, readability and relevance of the booklet. A Linkert scale of 0 to 4 points was used (0 - not applicable, 1 totally / difficult to agree 2 - partially agree / slightly difficult 3 - agree / easy 4 - totally agree / very easy), and the language of the questionnaires was adapted for each of the populations.

The group of experts, chosen by convenience, included specialists in clinical communication, speech and language therapist, psychologists, psychiatrists, neurologists, family physicians, nurses and physical therapists with at least 1 year of clinical practice. Patients and caregivers were recruited for those attending an outpatient clinic who agreed

to participate in the study. Patients unable to read or with cognitive impairment were excluded.

In accordance with the literature a score of 3 or higher was defined for validation [12, 49]. To verify the concordance of responses between experts and in the target population the Chi-Square adjustment test (x^2) was applied.

Data analysis was performed using descriptive and inferential statistics, using SPSS-24.0 software (Statistical Package for the Social Sciences).

Results

The total sample of the experts consisted of 23 participants, the majority of whom were females (n = 18; 78,3%) and males (n = 5; 21,7%). The difference between males and females is statistically significant (p=0,007).

Regarding the area of expertise of the expert participants, the majority was in the area of speech and language therapist (n = 18), in the area of nursing (n = 3); of family medicine (n = 2); and clinical communication (n = 3). They were aged between 23 and 60 years, mean age of 30,1 years ± 7,7. Regarding the number of years of clinical practice, they had a minimum of 1 years and a maximum of 25 years of clinical practice, a mean of 6,3 ± 6,3 years of clinical practice.

The degree of agreement was fulfilled (score higher than 3) in each of the six questions.

In the questions group “purpose and contents of the manual”, the most frequent answers were “agree” and “totally agree”. Most respondents agreed totally with a statistically significant difference with p <0,05, except for the item "Meets the needs of professionals working with neurological dysphagia" where opinions divide more between “agree” and “agree totally” with p> 0,05 (table 3).

Table 3. Answers from the experts in the purpose and contents of the manual items

Purpose and contents of the manual		n	%	*p*
It is consistent with the needs of patients	I agree	3	13,0	
	I totally agree	20	87,0	0,000
It is consistent with the needs of caregivers	I agree	3	13,0	
	I totally agree	20	87,0	0,000
	I agree	9	39,1	

Meets the needs of professionals working with neurological dysphagia	I totally agree	14	60,9	0,297
Presents scientifically correct information	I agree	5	21,7	
	I totally agree	18	78,3	0,007
The information is clear and objective	Partially agree	1	4,3	
	I agree	3	13,0	
	I totally agree	19	82,6	0,000
The information is consistent	I agree	4	17,4	
	I totally agree	19	82,6	0,002

Regarding the agreement of the statements of the structure and presentation of the manual we found a level of agreement above 99,3% (agree and agree totally). Most respondents agreed totally with a statistically significant difference with $p < 0,05$, except for the item "the number of pages is adequate" where opinions divide more between "agree" and "agree totally" with $p > 0,05$ (table 4).

Table 4. Answers from the experts in the structure and presentation of the manual items

Structure and presentation of the manual items		n	%	*p*
Images facilitate the understanding of information	I agree	5	21,7	
	I totally agree	18	78,3	0,007
The images are enough	partially agree	1	4,3	
	I agree	5	21,7	
	I totally agree	17	73,9	0,000
The presentation is adequate to provide guidance to patients and caregivers	I agree	5	21,7	
	I totally agree	18	78,3	0,007
Subtitles are appropriate	I agree	6	26,1	
	I totally agree	17	73,9	0,022
The highlighted text boxes / texts are appropriate	I agree	6	26,1	
	I totally agree	17	73,9	0,022
Font size is adequate	I agree	6	26,1	
	I totally agree	17	73,9	0,022
The number of pages is adequate	I agree	7	30,4	
	I totally agree	16	69,6	0,061
The information presents a logical sequence	I agree	4	17,4	
	I totally agree	19	82,6	0,002

All the experts considered that reading the manual is "easy"/"very easy", and most considered it "very easy" with a statistically significant difference (table 5).

Table 5. Answers from the experts in the readability items

Readability		n	%	*p*
As for reading the sentences of the manual, consider …	Easy	5	21,7	
	Very easy	18	78,3	0,007
Regarding the understanding of the information, consider …	Easy	6	26,1	
	Very easy	17	73,9	0,022

In the items related to “relevance of the manual”, most respondents agreed totally with a statistically significant difference with p <0,05. Of the experts, 76.8% considered "totally agree" (table 6).

Table 6. Answers from the experts in the relevance of the manual items

Relevance of the manual		n	%	*p*
The themes presented are the essential in communication with the target population	I agree	3	13,0	
	I totally agree	20	87,0	0,000
The manual enables the target population to acquire essential knowledge	I agree	8	34,8	
	I totally agree	15	65,2	0,144
The manual is suitable to be integrated into the clinical-patient-caregiver communication	I agree	5	21,7	
	I totally agree	18	78,3	0,007

The total sample of the target population consisted of 22 participants, (n = 14; 63,6%) female and males (n = 8; 36,4%), not being a statistically significant difference (p = 0,201).

In relation to the educational qualifications, of the 22 participants in the study, two had completed the 4th grade, two the 6th grade, two the 9th grade, one the high school, twelve concluded their degree and two the master's degree. Of the target population 59,1% were caregivers and 40,9% were patients with dysphagia.

Regarding age, participants in the target population were aged between 26 and 75 years, mean age 57,2 years ± 14,5. Participants in the target population group had at least 1 years and a maximum of 6 years of contact with Dysphagia, mean 2,1 years ± 1,2 of contact with dysphagia.

In the group of questions about "purpose and contents of the manual", in the items "it meets your needs" and "the information is enough" the answers were divided between "agree" and "totally agree" with a difference that is not statistically significant, $p > 0.05$. Most fully agreed with "the information is clear and objective" and “the manual is appropriate to provide guidance”, with a statistically significant difference (table 7).

Table 7. Answers from the target population in the purpose and contents of the manual items

Purpose and contents of the manual		n	%	*p*
It meets your needs	I agree	12	54,5	
	I totally agree	10	45,5	0,670
The information is enough	I agree	11	50,0	
	I totally agree	11	50,0	1,000
The information is clear and objective	Partially agree	1	4,5	
	I agree	8	36,4	
	I totally agree	13	59,1	0,007
The manual is appropriate to provide guidance	I agree	7	31,8	
	I totally agree	15	68,2	0,088

As for the "structure and presentation of the manual", most responded "I totally agree" (table 8).

Table 8. Answers from the target population in the structure and presentation of the manual items

Structure and presentation of the manual		n	%	*p*
Images facilitate the understanding of information	Totally disagree	1	4,5	
	Partially agree	1	4,5	
	I agree	5	22,7	
	I totally agree	15	68,2	0,000
The images are enough	Partially agree	1	4,5	
	I agree	8	36,4	
	I totally agree	13	59,1	0,007
Font size is adequate	Totally disagree	1	4,5	
	Partially agree	1	4,5	
	I agree	6	27,3	
	I totally agree	14	63,6	0,000
The number of pages is adequate	Partially agree	1	4,5	
	I agree	5	22,7	
	I totally agree	16	72,7	0,000

The information presents a logical sequence	Partially agree	1	4,5	
	I agree	10	45,5	
	I totally agree	11	50,0	0,016
The highlighted text boxes / texts are appropriate	Totally disagree	1	4,5	
	Partially agree	1	4,5	
	I agree	9	40,9	
	I totally agree	11	50,0	0,002
Subtitles are appropriate	Totally disagree	1	4,5	
	Partially agree	1	4,5	
	I agree	9	40,9	
	I totally agree	11	50,0	0,002
I had the motivation to read through	Partially agree	1	4,5	
	I agree	10	45,5	
	I totally agree	11	50,0	0,016

Most respondents answered "easy" to read (54,5%) and understand the information (50,0%), with a statistically significant difference.

Table 9. Answers from the target population in the readability items

Readability		n	%	*p*
As for reading the sentences of the manual, consider …	Difficult	1	4,5	
	Easy	12	54,5	
	Very easy	9	40,9	0,012
Regarding the understanding of the information, consider …	Difficult	1	4,5	
	Slightly difficult	1	4,5	
	Easy	11	50,0	
	Very easy	9	40,9	0,002

The opinions were divided as to the items "the manual allows you to acquire essential knowledge" and "the handbook helps you to communicate with the caregiver (if you are the patient) or with the patient (if you are the caregiver)", being $p > 0,05$, with no statistically significant difference between "agree"/"totally agree".

In the items "the manual helps you to ask questions to the professionals", "the handbook helps you communicate with healthcare professionals" and "the manual will help you to clarify your doubts if necessary", the most frequent answer was "I agree" with a statistically significant difference (table 10).

Table 10. Answers from the target population in the relevance of the manual items

Relevance of the manual		n	%	*p*
The manual helps you to put your questions to the professionals	I agree	14	63,6	
	I totally agree	8	36,4	0,201
The manual allows you to acquire essential knowledge	I agree	11	50,0	
	I totally agree	11	50,0	1,000
The handbook helps you communicate with the caregiver (if you are the patient) or with the patient (if you are the caregiver)	Partially agree	2	9,1	
	I agree	10	45,5	
	I totally agree	10	45,5	0,055
The handbook helps you communicate with healthcare professionals	Partially agree	1	4,5	
	I agree	13	59,1	
	I totally agree	8	36,4	0,007
The manual will help you to ask for help if necessary	Partially agree	1	4,5	
	I agree	10	45,5	
	I totally agree	11	50,0	0,016

After incorporating the suggestions of the two groups, the final version of the booklet information included 1. a definition of the concept of dysphagia - with an image to illustrate the difference between normal swallowing and dysphagia, causes of dysphagia and consequences; 2. an explanation about the thickeners and its use, ways to improve comfort and safety when eating and warning signs was also included; 3. a customizable part which permits to adapt specific dietary consistence for each patient. The titles chosen to identify each topic are directive and simple, for example, "I have Dysphagia and Now?; What is Dysphagia ?; How to prepare drinks?; Make your meals better."

The booklet counts 13 pages in A5 size, a cover and 6 pages with double-sided. An appealing layout with illustrations facilitates the understanding of the written information (Appendix 4).

The types of letters chosen were Dosis Book, Bold Dosage, Semi Bold Doses with letter sizes ranging from 15 to 30, in order to ensure that people with partial visual impairment were able to read.

Discussion

Experts and the target population were concordant, indicating that the booklet can be integrated into clinical practice and be beneficial. Studies have shown that the majority

of health professionals are insecure in their ability to support of behavioural changes as is the case of altered diet in dysphagic patients [50]. Written information can be a useful support for the delivery of information to patients and caregivers and enhance professional's communication efficacy [51, 52].

The present results underscore the importance of communication about their disorder and its treatment for the target population. Some studies correlate the discourse form and content of health professionals with the confidence felt by the patients in the information transmitted [52, 53] Hesitation in speech and lack of information contributed to communication failures and adverse reactions in patients. Another negative factor in reported is incongruent information between team members [53]. Our findings of a high congruence among health professionals is in line with the need to standardize the information given to the patient.

Health professionals need to delivery to their patients written information designed to be readable and meet their individual needs. Although this patient-oriented approach was a purpose of the present manual, in terms of readability responses by the patients and caregivers group may indicate the need for a supplementary oral explanation [54]. These results reinforce the need for the use of verbal and non-verbal communication strategies by professionals, as desired by others groups of patients [55].

In addition to its use in communication between the patient and healthcare professionals, the manual ensures that information can be retained more easily and/or can be consulted later. Adequate information is essential for successful self-management of the disease and its symptoms, reducing anxiety on the part of patients and the costs associated with hospital visits. Others have reported that failure to recall or understand complex information may occur and has to be prevented by health professionals [12].

Our study presents limitations: the study was conducted, for convenience, in a hospital in the north of Portugal and with professionals working in the Porto district. The sample presents statistically significant differences between members of the expert validation group.

Conclusion

In patients with dysphagia, who need to introduce difficult changes in feeding behaviour, the present booklet was considered to convey useful information, and to facilitate patient-health professional communication. Neurological dysphagia is a serious disorder and can

be a prolonged condition representing a challenge for patients and their caregivers [2]. The changes in diet required by the disorder require the understanding of new concepts and the introduction of specific behaviours in the lives of patients and caregivers. Understanding how and why achieve this goal, what resources to use, and how to make possible to cope with the swallowing disease are important information to be individually delivered by health professionals [2, 27, 50]. Studies conducted in several clinical areas demonstrate that the more information is given, the more autonomous the patients are and the more satisfaction they demonstrate with communication. At the time of hospital discharge, however, the amount of information given to the patient and caregivers may be difficult to recall. Most doubts come about a week after discharge from hospital, and written, reliable, and accessible information may be a way to reduce hospital visits or possible complications [11, 12]

The used methodology to develop and validation a booklet is in accordance with articles with similar goals [12, 49, 51]. The index of agreement obtained, allow us to consider the manual a tool accepted by experts, patients with dysphagia and caregivers, providing a strong argument to include the booklet in clinical practice.

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ARTIGO DE INVESTIGAÇÃO II

Information at discharge in patients with neurological dysphagia - impact on satisfaction with communication, happiness and information about the swallowing disorder

Article submitted to the journal "Stroke"

Title

Information at discharge in patients with dysphagia - impact on satisfaction with communication, happiness and information about the swallowing disorder

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Abstract

Dysphagia has consequences for patients and their caregivers, at the physiological and psychosocial level. Although the psychological impact of dysphagia can be devastating, research has privileged the physiological and clinical outcomes of the disorder.

The purpose of this study was to apply an original booklet to patients with dysphagia and caregivers during hospital admission and to analyse differences in the level of subjective feeling of happiness, satisfaction with communication and knowledge about dysphagia compared to the traditional method of delivery of information.

A convenience sample of 27 patients with neurological dysphagia was divided into an experimental group (n = 14) who received the booklet and a control group (n = 13), submitted to the routine information procedures. Participants were surveyed at two moments (T1 and T2) regarding subjective well-being – Subjective Happiness Scale and satisfaction with the communication - Satisfaction Survey adapted from Patients satisfaction with the interview assessment questionnaire. At T2 knowledge about dysphagia was also assessed. Evaluation of type and severity of dysphagia was performed in both groups.

Statistically significant higher level of knowledge about dysphagia was found in the experimental group, but not regarding the subjective feeling of happiness and satisfaction with communication.
The results from this study provide an argument for combining verbal and written information at discharge. The use of the booklet made a significant contribution to patients' knowledge.

Keywords

Discharge Information; Neurological Dysphagia; Hapiness; Healthcare Satisfaction;

Introduction

Dysphagia is a serious disorder with the potential of psychologically and socially affect patients [1]. Consequences may include malnutrition, dehydration and respiratory complications which can affect the patient's quality of life and are responsible for increasing number of hospital admissions. In psychosocial terms the effect of dysphagia can be devastating, compromising patients wellbeing [1, 2].
The food modifications imposed by dysphagia can make the meal time uncomfortable, difficult and even cause physical and emotional suffering. For humans, food goes far beyond caloric and water requirements for their survival. Eating is also a social and pleasurable act for the human being. Food should also be seen as a source of pleasure, mediated by different flavours, consistencies and appearances [1-4].
Adaptations imposed by the presence of dysphagia lead to food selection and restriction modifying social activities and daily routines [1, 2].
For the effective management of oropharyngeal dysphagia, it is important to consider the patient's functional health status and to assess the impact of dysphagia on functional and psychosocial aspects [1]. A diagnosis of dysphagia alone or with other functional comorbidities is related to a poorer prognosis of patient rehabilitation. This ratio is due to the risk of malnutrition during post-hospitalization and the risk of respiratory complications that interfere with rehabilitation [1, 5]. Dehydration is another possible consequence that interferes with the recovery of the patient, since with diet modification the patient does not present pulmonary risks but the water supply may not be the desired

one. The use of thickener is related to a reduction of fluid intake and its use already impair the water supply [6, 7].

There is a paucity of studies regarding the psychosocial impact of dysphagia. This chronic condition erodes patient's quality of life, psychosocial well-being and satisfaction [8].

Comprehensible information for patients and caregivers is known to enhance satisfaction with health care and reduced psychological impact of the disease [9]. Studies carried out in several clinical areas indicate that patients desire for more information about symptoms, biopsychosocial consequences, pain management and therapy management [10-13]. The information received at the time of hospital discharge for example is described by the patients as insufficient and generalized. Studies indicate a preference for individualized information, complete and simple. The information allows patients to better manage therapy, having a positive impact on anxiety management. More informed patients and caregivers are more autonomous in self-management of symptoms and therapy allowing more informed decisions [9, 11, 12].

The information given to the patient allows him to create a realistic perspective and expectations of his illness, facilitating the assessment and management of unwanted changes. Planning the information to be given before discharge is important to prevent most of the doubts after discharge [9, 11, 12]. During the hospitalization period after the diagnosis, it is necessary to explain to the patients with dysphagia how they will prepare their drinks, what changes need to be made in the diet, swallowing strategies, signs that they should be aware of and what the rehabilitation plan will be [1, 5, 13]. It is essential to ensure that all professionals who are part of the team are aware of the safest diet for each patient and that the language used by everyone is standardized [1, 13]. The absence of clear and definite terminology capable of guiding the production of different food consistencies may compromise the patient's clinical condition and the evolution of swallowing therapy, since it is not guaranteed that the patient received exactly the diet indicated by the speech and language therapist after clinical and instrumental evaluation. Written information can avoid confusion in the language used and consequently in the diet adopted [1, 13].

The purpose of this explorative study was to apply an original booklet containing information about dysphagia to a group of patients and to analyse the impact of its application in subjective wellbeing, satisfaction with communication and knowledge about dysphagia, when compared with the routine delivery of information about the disease.

Methods

Patients with neurological dysphagia according to the Functional Oral Intake Scale (FOIS) [14] (Annex 1) equal to or greater than three, diagnosed with dysphagia for less than two weeks and hospitalized in an acute hospital setting were selected to this study. Patients with no conditions from reading or understanding the manual, like language alterations, cognitive deficits and/or illiteracy were excluded.

Patients fulfilling the inclusion criteria who agreed to participate in the study were randomly allocated to the experimental and the control group using an online software [15]. Assessment was performed at T1, after the speech and language therapist established the first contact with the patient, and evaluated the degree of dysphagia. Patents fulfilled a sociodemographic questionnaire (Appendix 5), the Portuguese version of the Subjective Happiness Scale (SHS) [16] (Annex 2) and the adapted version of the Patients Satisfaction with the Interview Assessment Questionnaire (PSIAQ) [17] (Appendix 6).

A week later (T2) the booklet was presented to the patients of the experimental group, during a therapeutic session. Both groups of patients were requested to fill in the same battery of instruments, and in the intervention group an Inquiry evaluating the information received (Appendix 7). In the control group, the therapeutic session was performed without the presentation of the manual.

Authorization was requested and obtained from the ethics committee of two hospitals with acute hospitalization in the north of Portugal (Annex 3). All the patients received oral and written information about the study protocol and signed an informed consent form.

Data analysis was performed using descriptive and inferential statistics, using SPSS-24.0 software (Statistical Package for the Social Sciences). For the comparison of two groups, the Mann-Withney test was applied and for comparison of the moment before and the moment after the intervention, the Wilcoxon test was applied for a population median. The chi-square test was used in the association of the information questions patients have about dysphagia as a function of the group.

Results

Sociodemographic characterization - The sample included 27 participants divided into a control group (n=13, 48,2%) and an experimental group (n = 14, 51,9%). The majority of the patients were male (81,45%) , aged between 39 and 80 years, mean 64,5 and standard deviation 9,7. As for literacy, 14,8% completed graduation and 70,4% had an undergraduate degree.

Of the 27 participants in the study, 14 (51,8%) lived with their spouses, five (18,5%) lived with their son or daughter, four (14,8%) lived with others not included in the options, there (11,1%) live with caregivers and one participant (3,7%) lives alone.

Regarding the clinical diagnosis, 81,5% of the participants suffered a stroke, 3,7% had traumatic brain injury and 14,8% of the participants had other neurological disease.

Patients Satisfaction with the Interview Assessment Questionnaire - The comparison of the patient satisfaction with the communication, revealed a statistically significant difference between T1 and T2 (Table 1) namely in the question "ability of the health professionals to reassure me". At both moments the mean level of satisfaction was higher in the experimental group.

Table 1. Comparison of the patient satisfaction questions at each of the moments, before and after the intervention, between the groups

Patients Satisfaction	Control Group		Experimental Group		
	mean	sd	mean	sd	*p*
Before (t1)					
Satisfaction (Total)	3,50	0,35	3,51	0,22	0,883
The way in which health professionals presented themselves	3,69	0,48	3,57	0,51	0,524
The way in which health professionals have received me	3,77	0,44	3,43	0,51	0,077
The clarifications regarding my eating problem	3,46	0,52	3,43	0,51	0,866
The ability to listen to my food concerns	3,38	0,51	3,36	0,50	0,885
The way health professionals answered my questions	3,46	0,52	3,50	0,52	0,845
The ability of health professionals to reassure me	3,38	0,51	3,86	0,36	0,013
The availability of health professionals	3,54	0,52	3,43	0,51	0,575
Overall, the way you communicated with the team	3,31	0,48	3,50	0,52	0,319
After (t2)					
Satisfaction (Total)	3,40	0,38	3,58	0,22	0,148

The way in which health professionals presented themselves	3,62	0,51	3,64	0,50	0,885
The way in which health professionals have received me	3,77	0,44	3,57	0,51	0,285
The clarifications regarding my eating problem	3,31	0,63	3,43	0,51	0,657
The ability to listen to my food concerns	3,31	0,75	3,36	0,50	0,978
The way health professionals answered my questions	3,31	0,63	3,71	0,47	0,075
The ability of health professionals to reassure me	3,23	0,44	3,86	0,36	0,001
The availability of health professionals	3,31	0,48	3,57	0,51	0,176
Overall, the way you communicated with the team	3,38	0,51	3,50	0,52	0,554

From the comparison of the patient satisfaction questions with the communication, in each of the groups, between the moments before and after the intervention (table 2), there was a statistically significant difference in the control group. In total satisfaction the average satisfaction level of the patients was higher in t1.

Table 2. Comparison of patient satisfaction questions in each of the groups, between the moments before and after the intervention.

Patients Satisfaction	before (t1)		after (t2)		
	mean	sd	mean	sd	*p*
Control Group					
Satisfaction (Total)	3,50	0,35	3,40	0,38	0,026
The way in which health professionals presented themselves	3,69	0,48	3,62	0,51	0,317
The way in which health professionals have received me	3,77	0,44	3,77	0,44	1,000
The clarifications regarding my eating problem	3,46	0,52	3,31	0,63	0,317
The ability to listen to my food concerns	3,38	0,51	3,31	0,75	0,655
The way health professionals answered my questions	3,46	0,52	3,31	0,63	0,317
The ability of health professionals to reassure me	3,38	0,51	3,23	0,44	0,157
The availability of health professionals	3,54	0,52	3,31	0,48	0,083
Overall, the way you communicated with the team	3,31	0,48	3,38	0,51	0,317
Experimental Group					
Satisfaction (Total)	3,51	0,22	3,58	0,22	0,174

The way in which health professionals presented themselves	3,57	0,51	3,64	0,50	0,317
The way in which health professionals have received me	3,43	0,51	3,57	0,51	0,157
The clarifications regarding my eating problem	3,43	0,51	3,43	0,51	1,000
The ability to listen to my food concerns	3,36	0,50	3,36	0,50	1,000
The way health professionals answered my questions	3,50	0,52	3,71	0,47	0,083
The ability of health professionals to reassure me	3,86	0,36	3,86	0,36	1,000
The availability of health professionals	3,43	0,51	3,57	0,51	0,157
Overall, the way you communicated with the team	3,50	0,52	3,50	0,52	1,000

Subjective Happiness Scale – Comparing subjective happiness in each moment, before and after the intervention, between the groups (table 3), showed the existence of statistically significant differences, with a mean happiness score higher in the control group (Table 3).

Table 3. Comparison of the happiness issues of the patients in each of the moments, before and after the intervention between the groups

Subjective Happiness Scale	Control Group		Experimental Group		
	mean	sd	mean	sd	*p*
before (t1)					
In general, I consider myself (Happy / Unhappy)	4,31	1,49	3,93	0,73	0,284
Compared to other people like me, I consider myself (Less happy / happier)	4,46	1,45	3,86	0,77	0,218
Some people are very happy. They love life despite what is happening, getting the best of the available	4,54	1,56	3,00	1,11	0,008
Some people are not very happy. Although they are not depressed, they never seem as happy as they could be	4,31	1,70	2,57	0,76	0,002
after (t2)					
In general, I consider myself (Happy / Unhappy)	3,85	1,46	4,21	0,70	0,323
Compared to other people like me, I consider myself (Less happy / happier)	4,31	1,49	4,29	0,99	0,743

Some people are very happy. They love life despite what is happening, getting the best of the available	4,54	1,39	3,00	1,11	0,005
Some people are not very happy. Although they are not depressed, they never seem as happy as they could be	4,15	1,63	2,71	0,91	0,004

Comparison the questions of the Subjective Happiness Scale in each of the groups, between the moments before and after the intervention (Table 4), detected statistically significant differences.

Table 4. Comparison of patient happiness issues in each of the groups, between the moments before and after the intervention

Scale of Subjective Happiness	before		after		
	mean	sd	mean	sd	*p*
Control Group					
In general, I consider myself (Happy / Unhappy)	4,31	1,49	3,85	1,46	0,014
Compared to other people like me, I consider myself (Less happy / happier)	4,46	1,45	4,31	1,49	0,157
Some people are very happy. They love life despite what is happening, getting the best of the available	4,54	1,56	4,54	1,39	1,000
Some people are not very happy. Although they are not depressed, they never seem as happy as they could be	4,31	1,70	4,15	1,63	0,317
Experimental Group					
In general, I consider myself (Happy / Unhappy)	3,93	0,73	4,21	0,70	0,046
Compared to other people like me, I consider myself (Less happy / happier)	3,86	0,77	4,29	0,99	0,014
Some people are very happy. They love life despite what is happening, getting the best of the available	3,00	1,11	3,00	1,11	1,000
Some people are not very happy. Although they are not depressed, they never seem as happy as they could be	2,57	0,76	2,71	0,91	0,414

Evaluation of information about dysphagia in each group revealed statistically significant differences (table 5).

In the question "I know how to prepare my drinks without putting myself in danger", the prevalence of agreement was higher in the experimental group (78.6%), with a statistically significant difference (p = 0.007) between the groups. In the question "I know that my difficulty in swallowing influences my overall health" (p = 0.006), the prevalence of agreement was higher in the experimental group (66.7%). As in the questions "I know there are some signs that I should be aware of when I am eating" and "If necessary, I can explain how my meals should be prepared", where the prevalence was also higher in the experimental group, with differences statistically significant. In the last question, "If necessary, I can explain how my meals should be prepared", 100% of the participants in the experimental group answered "I agree".

Table 5. Comparison of the level of knowledge about dysphagia between the different groups

	Control Group		Experimental Group		Total		*p*
In relation to my eating problem it is clear to me why it came							
I do not agree	0	0,0%	2	100%	2	100%	
I agree	13	52,0%	12	48,0%	25	100%	0,481
I know that Dysphagia is a difficulty in swallowing caused by my disease							
I agree	13	48,1%	14	51,9%	27	100%	
I know what I can eat without putting myself in danger							
I do not agree	5	83,3%	1	16,7%	6	100%	
I agree	8	38,1%	13	61,9%	21	100%	0,077
I know how to prepare my drinks without putting myself in danger							
I do not agree	10	76,9%	3	23,1%	13	100%	
I agree	3	21,4%	11	78,6%	14	100%	0.007
I know that my difficulty in swallowing can endanger my health, because if I do not follow the directions, I may have trouble breathing							
I do not agree	3	100%	0	0,0%	3	100%	
I agree	10	41,7%	14	58,3%	24	100%	0,098
I know that my difficulty in swallowing influences my overall health							
I do not agree	6	100%	0	0,0%	6	100%	
I agree	7	33,3%	14	66,7%	21	100%	0,006
I know I must be careful where I cook my meals and the way I sit at the table							
I do not agree	7	70,0%	3	30,0%	10	100%	
I agree	6	35,3%	11	64,7%	17	100%	0,12
I know there are some signs that I must be aware of when I am eating							

I do not agree	8	80,0%	2	20,0%	10	100%	
I agree	5	29,4%	12	70,6%	17	100%	0,018
If necessary, I can explain how my meals should be prepared							
I do not agree	13	65,0%	7	35,0%	20	100%	
I agree	0	0,0%	7	100%	7	100%	0,006
I know I can do therapy to improve what I eat and how I do it							
I do not agree	1	100%	0	0,0%	1	100%	
I agree	12	46,2%	14	53,8%	26	100%	0,481

Discussion

The results showed a positive impact of the booklet utilization which allowed the patients to acquire more knowledge, mainly in the items "I know how to prepare my drinks without putting myself in danger", "I know that my difficulty in swallowing influences my overall health", "I know there are some signs that I should be aware of when I am eating" and "If necessary, I can explain how my meals should be prepared".

The greater knowledge may indicate that the patients included in the intervention group will be less susceptible to clinical complications after discharge, since they will be supplied with information they can consult as many times as needed.

In the control group, satisfaction with communication decreased significantly between the two moments. Over time patients may feel the need for greater communication with the team. The utilization of a booklet appears to have no significant impact on the satisfaction with communication although a trend was found to higher levels of satisfaction especially in the item related to how professionals respond to their questions.

A limitation of this study is the small number of patients included. However, it represents the complete speech and language therapy caseload. The time period between the two collection moments was adjusted so that no sample was lost because of early discharge.

We have therefore made the assumption that an accurate representation of patient care in hospital was gained from this small sample.

Conclusion

The results from this study provide an argument for combining verbal and written information about dysphagia at discharge. The literature shows, the more informed patients present less complications and less often use health services. Patients' information enables health complications [9-12].

The use of the booklet made a significant contribution to patients' knowledge. Patients are more informed about how to prepare their meals, what signs they should be aware of, and that their swallowing problem compromises their overall health.

Apart from the knowledge about dysphagia, the use of booklet suggests that patients feel that the professionals try harder to answer their questions. The results suggest that the use of booklet in clinical practice improves patients' knowledge regarding dysphagia and allows a recognition of the quality of communication established with the health team.

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Annex

Annex 1: Functional Oral Intake Scale (FOIS)

Annex 2: Portuguese version of the Subjective Happiness Scale (SHS)

Annex 3: Ethical approval by Evaluation Committee for Academic Works and the Ethical Committee of the Braga Hospital and CUF Porto Hospital

Annex 1

ESCALA FOIS – VERSÃO PORTUGUESA
TRADUÇÃO DE LOPES & NOGUEIRA (2015)

Circle the appropriate response.
Assinale a resposta mais apropriada.

Funcional Oral Intake Scale (FOIS)	
Level 1 *Nível 1*	Nothing by mouth. *Nada por via oral*
Level 2 *Nível 2*	Tube dependent with minimal attempts of food or liquid. *Entubado, com tentativas mínimas de ingestão de sólidos ou líquidos por via oral.*
Level 3 *Nível 3*	Tube dependent with consistent oral intake of food or liquid. *Entubado, com ingestão regular de sólidos ou líquidos por via oral.*
Level 4 *Nível 4*	Total oral diet of a single consistency. *Alimentação por via oral utilizando apenas uma única consistência.*
Level 5 *Nível 5*	Total oral diet with multiple consistencies, but requiring special preparation or compensations. *Alimentação por via oral utilizando várias consistências, e necessitando de preparação especial ou posturas compensatórias.*
Level 6 *Nível 6*	Total oral diet with multiple consistencies without special preparation, but with specific food limitations. *Alimentação por via oral utilizando várias consistências, sem preparação especial mas com limitação para alimentos específicos.*
Level 7 *Nível 7*	Total oral diet with no restrictions. *Alimentação por via oral, sem restrições.*

Annex 2

ESCALA SHS – VERSÃO PORTUGUESA
TRADUÇÃO DE JL PAIS RIBEIRO (2012)

FELICIDADE SUBJECTIVA

Para cada uma das questões e/ou afirmações seguintes, por favor assinale na escala, entre 1 e 7, a que parece que melhor o/a descreve

1. Em geral, considero-me:

1	2	3	4	5	6	7
Uma pessoa que não é muito feliz						Uma pessoa muito feliz

2. Comparativamente com as outras pessoas como eu, considero-me:

1	2	3	4	5	6	7
Menos feliz						Mais feliz

3. Algumas pessoas são geralmente muito felizes. Elas gozam a vida apesar do que se passa à volta delas, conseguindo o melhor do que está disponível. Em que medida esta caracterização o/a descreve a si?

1	2	3	4	5	6	7
De modo nenhum						Em grande parte

4. Algumas pessoas geralmente não são muito felizes. Embora não estejam deprimidas, elas nunca parecem tão felizes quanto poderiam ser. Em que medida esta caracterização o/a descreve a si?

1	2	3	4	5	6	7
De modo nenhum						Em grande parte

OBRIGADO PELA SUA COLABORAÇÃO

Annex 3

cuf porto hospital

Exma. Senhora
Terapeuta Juliana Ferreira

N/ Ref. HCP/CES – 018/18

Porto, 22 de Junho de 2018

Assunto: 'Information on discharge in patients with neurologic dysphagia – impact on clinical outcome, therapeutic adherence and quality of life'

Exma. Senhora Terapeuta Juliana Ferreira,

Vimos por este meio informar que após análise do estudo acima identificado o parecer ético é favorável.
Segue em anexo o formulário de avaliação.

Com os meus melhores cumprimentos,

P'la Comissão de Ética
Sara Martins, Enf.

Hospital Braga

Comissão de Ética para a Saúde

Data: 12 de Julho de 2018

Refª 71/2018

Relator: Paulo Silva

Parecer emitido em reunião plenária de 10 de Julho de 2018

Nos termos dos Nº 1 e 6 do Artigo 16º da Lei Nº 21/2014, de 16 de Abril, a Comissão de Ética para a Saúde do Hospital de Braga (CESHB) em relação ao estudo **"O impacto da informação no momento da alta na evolução clínica em doentes neurológicos com disfagia"**, de que é investigadora principal a Dra. Juliana Patrícia Figueiras Ferreira, orientadora a Professora Doutora Margarida Maria Carvalho de Figueiredo Ferreira Braga, e que decorrerá no âmbito do Serviço de Medicina Física e Reabilitação do Hospital de Braga, emite o seguinte parecer:

a) O estudo pretende avaliar o impacto do uso de um manual informativo a disponibilizar no momento da alta a pacientes pós-AVC com disfagia que irão para contexto domiciliário, na evolução clínica e de qualidade de vida; avaliar a adesão e grau de satisfação aos procedimentos alimentares propostos no momento de alta; e avaliar o bem-estar psicológico dos pacientes que integram o estudo. Neste contexto, trata-se de um estudo clínico multicêntrico, com intervenção, a desenvolver no âmbito do Mestrado em Comunicação Clínica da Faculdade de Medicina da Universidade do Porto;

b) A colheita de dados será efetuada através da aplicação de um conjunto de instrumentos de colheita de dados, após a divisão aleatória dos participantes em 2 grupos – grupo experimental e grupo de controle. O grupo de controle será submetido à informação habitual no momento de alta, e ao grupo de intervenção será facultado o manual informativo. No momento de alta os participantes de ambos os grupos serão avaliados com os instrumentos referidos. Esta avaliação será repetida após 1 mês de alta em ambos grupos.

Os instrumentos de colheita de dados a utilizar serão os seguintes:

- Caracterização sociodemográfica – questionário original construído para o presente estudo;

- Avaliação da qualidade respiratória – questionário original de avaliação da função respiratória;

- Avaliação da disfagia – versão portuguesa do *Function Oral Intake Scale* (FOIS);

- Avaliação da adesão aos procedimentos alimentares – escala de adesão à terapêutica adaptada;

- Questionário original de avaliação de barreiras e facilitadores da adaptação á alimentação modificada e de adesão e satisfação com os procedimentos alimentares.

- Bem-estar psicológico e qualidade de vida – utilização da versão Portuguesa do SF-36 e da Escala de Felicidade Subjetiva (EFS).

Neste sentido, não estão associados ao estudo riscos previsíveis;

c) O protocolo é adequado e existem planos de divulgação dos resultados proporcionais ao âmbito de uma Dissertação de Mestrado;

d) A investigadora principal e orientadora possuem aptidão para a realização do estudo;

e) Existem condições materiais e humanas necessárias à realização do estudo clínico;

f) O estudo não acarretará abuso de recursos, não implicando custos para os participantes, nem para o Hospital de Braga. Os doentes nunca terão de se deslocar para participar no estudo, sendo que este decorrerá no período de internamento e de acompanhamento em ambulatório;

g) A população abrangida serão todos os pacientes adultos em contexto pós-Acidente Vascular Cerebral, internados em contexto hospitalar de agudos com grau de disfagia, de acordo com a *Function Oral Intake Scale* (FOIS) igual ou superior a 3. O recrutamento dos doentes será efetuado através de um elo de ligação da instituição (Dra. Maria João Vieira), a terapeuta da fala que atende

habitualmente doentes com patologia neurológica com disfagia. Os dados serão recolhidos em contexto de internamento e de ambulatório no serviço de Medicina Fisica e Reabilitação até ao dia 14/09/2018.

Pacientes com alterações de linguagem e/ou défices cognitivos que impossibilitem a leitura ou compreensão do manual; escolaridade baixa ou inexistente que impossibilite a leitura e compreensão do manual, bem como pacientes que sejam transferidos para outra unidade de cuidados de saúde, estarão excluídos do estudo.

h) Não foram referidas situações de conflito de interesses;

i) Não haverá acompanhamento clínico dos participantes depois do 1º mês após alta;

j) Existe um adequado procedimento de obtenção de consentimento informado, incluindo as informações a prestar aos participantes. Existe o compromisso de que os dados recolhidos serão tratados de forma anónima, e que será garantida a sua confidencialidade ao longo de todo o processo.

Concluindo, o estudo cumpre as normas da Bioética e nada há a opor à sua realização.

O Presidente da CESHB

(Dr. Juan Garcia)

Appendix

Appendix 1: Consent form for the focus group

Appendix 2: Focal group guide

Appendix 3: Validation questionnaires (experts and target population)

Appendix 4: Booklet

Appendix 5: Sociodemographic questionnaire

Appendix 6: Adapted version of the Patients Satisfaction with the Interview Assessment Questionnaire (PSIAQ)

Appendix 7: Original knowledge questionnaire

Appendix 1:

Formulário de consentimento

Objetivo do Grupo de foco: Avaliação do manual de orientações para pessoas com disfagia «Tenho Disfagia e agora?».

A avaliação do manual consiste na recolha de opiniões e sugestões acerca da informação e formato gráfico do manual. Esta avaliação permitirá melhorar o manual e irá decorrer em grupo onde cada pessoa pode expressar a sua opinião.

Se o consentir, a reunião será gravada em áudio.

(Nome) _____

, concordo em participar na avaliação do manual de orientações a pessoas com disfagia «Tenho Disfagia e agora?», especificado acima.

Compreendi que concordar em participar significa que estou disposto a:

1. Aceitar participar neste grupo focal

2. Permitir a gravação áudio desta reunião

Compreendo que a minha participação é voluntária e que posso interromper a minha participação em qualquer fase do processo sem ser penalizado ou desfavorecido de qualquer forma.
Compreendo que todos os dados que o investigador extrai do grupo de focal serão apenas para relatórios ou publicação de resultados e em nenhuma circunstância, serão colocados nomes ou características de identificação.

Nome do participante:

Assinatura:

Appendix 2:

Modelo de Facilitação de Reunião de Grupo Focal

Abertura (5 minutos)

"Olá, boa tarde. Hoje gostaria de conversar convosco sobre o manual que vos foi apresentado, o manual de orientações a pessoas com disfagia “Tenho Disfagia e Agora?”.

Estamos a recolher as vossas opiniões e sugestões acerca do manual, quanto à informação que contém, à sua organização, apresentação e utilidade. Gostaríamos também de obter a vossa apreciação sobre as imagens, cores e tipo letra.

Há alguma pergunta?"

Responder às perguntas dos participantes.

"Vou falar-vos sobre algumas regras para a reunião de hoje. Primeiro, pedia que desligassem os telemóveis para evitar interrupções. Para o melhor funcionamento da reunião, pedia que todos expressassem a sua opinião, falando um de cada vez de modo a ouvir a opinião de todos e, por favor, não interrompam ninguém.

Gostaria de explicar que a opinião que derem no decorrer da reunião apenas será utilizada para melhorar o manual e para registar no trabalho de investigação, sem identificação dos participantes.

Um dos meus trabalhos é moderar esta conversa para garantir que iremos abordar todos os tópicos que planeamos previamente.

Há alguma pergunta?”

Responder às perguntas dos participantes.

“Vamos começar, pedia para dizerem o nome e outras informações que queiram facultar. Temos 25 minutos."

Apontar aleatoriamente para alguém para começar.

1. Pergunta

Pergunta Geral: O que acharam em relação à informação que foi colocada no manual?

Pergunta Específica: Acharam simples ou difícil de perceber? Alteravam alguma parte? Acrescentavam alguma informação?

2. Pergunta Geral: O que acharam em relação às imagens, cores e tipo de letra?

Pergunta Específica: Acharam os esquemas uteis? O tamanho de letra é adequado? Alteravam alguma parte?

"Alguém quer dar alguma sugestão ou colocar alguma pergunta?"

Responder às perguntas/ escutar sugestões

"Queria agradecer terem participado no grupo e estarem a contribuir para o sucesso da elaboração de um manual que permita orientar melhor pessoas com disfagia e os seus cuidadores."

Appendix 3:

AVALIAÇÃO POR PERITOS

O manual "Tenho disfagia e agora?" foi elaborado no âmbito do mestrado em Comunicação Clínica da Faculdade de Medicina da Universidade do Porto e pretende facilitar a comunicação doente-profissional de saúde, informar o doente e facilitar e aumentar a adesão às adaptações alimentares impostas pela disfagia.

Este questionário tem como objetivo avaliar o manual. Queremos perceber a sua opinião quanto à informação que o manual contém, à sua organização, conteúdo, utilidade e quanto à apresentação gráfica (imagens, cores e tipo de letra).

Agradecemos a sua disponibilidade para preencher o seguinte questionário, é muito importante a sua participação!

IDADE: _____

SEXO: FEMININO ☐ MASCULINO ☐

HABILITAÇÕES LITERÁRIAS: LICENCIATURA ☐ MESTRADO ☐ DOUTORAMENTO ☐

ÁREAS DE ESPECIALIZAÇÃO: COMUNICAÇÃO CLÍNICA ☐ TERAPIA DA FALA ☐

PSICOLOGIA/PSIQUIATRIA ☐ MEDICINA GERAL E FAMILIAR ☐ NEUROLOGIA ☐

ENFERMAGEM ☐

Item Objetivo e conteúdo do manual	Discordo totalmente	Concordo parcialmente	Concordo	Concordo Totalmente	Não se aplica
1. É coerente com as necessidades dos doentes	☐	☐	☐	☐	☐
2. É coerente com as necessidades dos cuidadores	☐	☐	☐	☐	☐
3. Atende as necessidades dos profissionais que trabalham com pessoas com disfagia neurológica	☐	☐	☐	☐	☐
4. Apresenta informação cientificamente correta	☐	☐	☐	☐	☐
5. A informação é clara e objetiva	☐	☐	☐	☐	☐
6. A informação é coerente	☐	☐	☐	☐	☐
Estrutura e apresentação do manual	Discordo totalmente	Concordo parcialmente	Concordo	Concordo Totalmente	Não se aplica

1. As imagens facilitam a compreensão da informação	☐	☐	☐	☐	☐
2. As imagens são suficientes	☐	☐	☐	☐	☐
3. A apresentação é adequada para fornecer orientações aos pacientes e cuidadores	☐	☐	☐	☐	☐
4. Os subtítulos são adequados	☐	☐	☐	☐	☐
5. As caixas de texto/textos em destaque são adequados	☐	☐	☐	☐	☐
6. O tamanho de letra é adequado	☐	☐	☐	☐	☐
7. O número de páginas é adequado	☐	☐	☐	☐	☐
8. As informações apresentam uma sequência lógica	☐	☐	☐	☐	☐
Legibilidade	Difícil	Ligeiramente difícil	Fácil	Muito fácil	Não sei
1. Quanto à leitura das frases do manual, considera…	☐	☐	☐	☐	☐
2. Quanto à compreensão da informação, considera…	☐	☐	☐	☐	☐
Relevância do manual	Discordo totalmente	Concordo parcialmente	Concordo	Concordo Totalmente	Não se aplica
1. Os temas apresentados são os essenciais na comunicação com a população-alvo	☐	☐	☐	☐	☐
2. O manual permite à população-alvo adquirir conhecimentos essenciais	☐	☐	☐	☐	☐
3. O manual é adequado para ser integrado na comunicação clínico-paciente-cuidadores	☐	☐	☐	☐	☐

AVALIAÇÃO PELA POPULAÇÃO-ALVO

O manual "Tenho disfagia e agora?" foi elaborado no âmbito do mestrado em Comunicação Clínica da Faculdade de Medicina da Universidade do Porto e pretende facilitar a comunicação doente-profissional de saúde, informar o doente e facilitar e aumentar a adesão às adaptações alimentares impostas pela disfagia.

Este questionário tem como objetivo avaliar o manual. Queremos perceber a vossa opinião quanto à informação que o manual contém, à sua organização, conteúdo, utilidade e quanto à apresentação gráfica (imagens, cores e tipo de letra).

Agradecemos a sua disponibilidade para preencher o seguinte questionário, é muito importante a sua participação!

IDADE: _____

SEXO: FEMININO ☐ MASCULINO ☐

HABILITAÇÕES LITERÁRIAS: 1º CICLO ☐ 2º CICLO ☐ 3º CICLO ☐ ENSINO SECUNDÁRIO ☐

LICENCIATURA ☐ MESTRADO ☐ DOUTORAMENTO ☐

TIPO DE CONTACTO COM A DISFAGIA: CUIDADOR ☐ PACIENTE ☐

TEMPO DE CONTACTO COM A DISFAGIA: _____

Item Objetivo e conteúdo do manual	Discordo totalmente	Concordo parcialmente	Concordo	Concordo Totalmente	Não se aplica
1. Vai de encontro às suas necessidades	☐	☐	☐	☐	☐
2. A informação é suficiente	☐	☐	☐	☐	☐
3. A informação é clara e objetiva	☐	☐	☐	☐	☐
4. O manual é adequado para fornecer orientações	☐	☐	☐	☐	☐
Estrutura e apresentação do manual	Discordo totalmente	Concordo parcialmente	Concordo	Concordo Totalmente	Não se aplica
1. As imagens facilitam a explicação da informação	☐	☐	☐	☐	☐
2. As imagens são suficientes	☐	☐	☐	☐	☐
3. O tamanho de letra é adequado	☐	☐	☐	☐	☐

4. O número de páginas é adequado	☐	☐	☐	☐	☐
5. As informações apresentam uma sequência lógica	☐	☐	☐	☐	☐
6. As caixas de texto/textos em destaque são adequados	☐	☐	☐	☐	☐
7. Os subtítulos são adequados	☐	☐	☐	☐	☐
8. Tive motivação para ler até ao fim	☐	☐	☐	☐	☐
Legibilidade	Difícil	Ligeiramente difícil	Fácil	Muito fácil	Não sei
1. Quanto à leitura das frases do manual, considera…	☐	☐	☐	☐	☐
2. Quanto à compreensão da informação, considera…	☐	☐	☐	☐	☐
Relevância do manual	Discordo totalmente	Concordo parcialmente	Concordo	Concordo Totalmente	Não se aplica
1. O manual ajuda-o a colocar as suas dúvidas aos profissionais	☐	☐	☐	☐	☐
2. O manual permite adquirir conhecimentos essenciais	☐	☐	☐	☐	☐
3. O manual ajuda-o a comunicar com o cuidador (se é o doente) ou com o doente (se é o cuidador)	☐	☐	☐	☐	☐
4. O manual ajuda-o a comunicar com os profissionais de saúde	☐	☐	☐	☐	☐
5. O manual irá ajudá-lo a pedir ajuda em caso de necessidade	☐	☐	☐	☐	☐

Appendix 4:


Tenho Disfagia...
e Agora?
Drª Juliana Ferreira
Professora Doutora Margarida Figueiredo Braga
Faculdade de Medicina da Universidade do Porto

O que é a Disfagia?

Engolir é um processo natural, comandado pelo cérebro.
O que comemos ou bebemos é levado, usualmente, de forma segura da boca até ao estômago, ou seja, sem que estas substâncias passem para as vias respiratórias.
Quando este processo é afetado, a pessoa pode sentir dificuldades em engolir tais como desconforto, sensação de que a comida fica presa, engasgamento fácil, vontade de tossir ou de limpar a garganta. Dizemos então que existe **disfagia**.

A disfagia é, assim, a dificuldade em engolir alimentos sólidos, líquidos e/ou saliva

Engolir normalmente **Disfagia**

Várias situações podem causar disfagia

Acidentes Vasculares Cerebrais (AVC)

Traumatismos Crânio - Encefálicos (TCE)

Outras doenças neurológicas (demência, doenças generativas, etc.)

Tumores de cabeça e pescoço

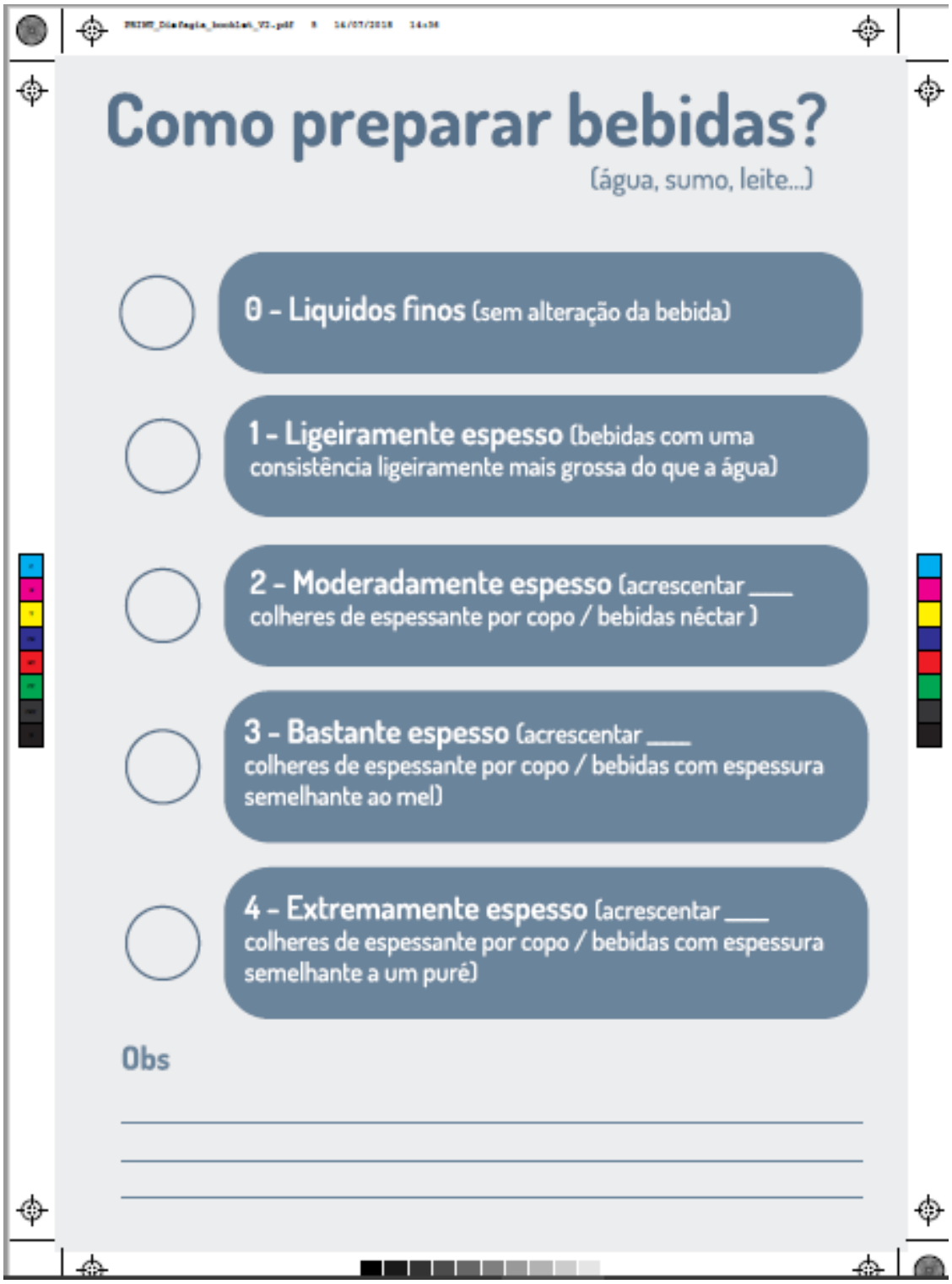
Envelhecimento normal

Consequências da disfagia

- As pessoas tendem a beber menos água, podendo ficar desidratadas.
- A alimentação adaptada pode ser menos atrativa e variada. As pessoas podem perder peso e/ou ficar desnutridas.
- A entrada de alimentos para a via respiratória pode provocar infeções respiratórias frequentes, pneumonias ou outras complicações graves, podendo levar as pessoas à morte.
- Em alguns casos pode implicar a utilização de sondas nasogástricas ou gastrostomia/PEG.

E agora?

Das opções que se seguem, estarão assinaladas as que se aplicam ao seu caso...


Como preparar bebidas?
(água, sumo, leite...)
0 - Liquidos finos (sem alteração da bebida)
1 - Ligeiramente espesso (bebidas com uma consistência ligeiramente mais grossa do que a água)
2 - Moderadamente espesso (acrescentar ___ colheres de espessante por copo / bebidas néctar)
3 - Bastante espesso (acrescentar ___ colheres de espessante por copo / bebidas com espessura semelhante ao mel)
4 - Extremamente espesso (acrescentar ___ colheres de espessante por copo / bebidas com espessura semelhante a um puré)
Obs

O que é o Espessante?

O espessante é apenas um pó branco, que não tem sabor ou cheiro. Por isso, não altera as bebidas que ficam apenas mais espessas. O espessante pode ser adicionado a qualquer líquido quente ou frio: café, leite, sumo, água, iogurte, batidos, bebidas com gás, etc.

Assim, evita-se que os líquidos entrem para a via respiratória, eliminando algumas das consequências da disfagia.

Existem vários tipos de espessante que podem ser adquiridos em farmácia.

Deve perguntar à equipa que o acompanha qual o tipo que melhor se adequa a si!

Como usar?

1. Colocar o pó num copo
2. Adicionar água, leite, sumo, chá... ou qualquer outra bebida
3. Misturar até dissolver completamente
4. Esperar durante uns segundos


Como preparar refeições?
7 - Alimentação regular/habitual
6 - Alimentos bem cozidos / moles
5 - Alimentos picados e humidificados
(por exemplo: alimentos fáceis de mastigar, alimentos cozidos e esmagados/picados, como fruta e vegetais. Os alimentos devem ser muito bem cozidos, adicione azeite, molhos, etc.)
4 - Alimentos tipo puré
(por exemplo: papa em puré; vegetais em puré; creme de carne ou peixe; puré de batata)
3 - Alimentos liquidificados
(por exemplo: papa de fruta, carne, peixe, vegetais mas passar antes no liquidificador. Não pode ser uma papa espessa/grossa)
Obs

Melhore as suas refeições!

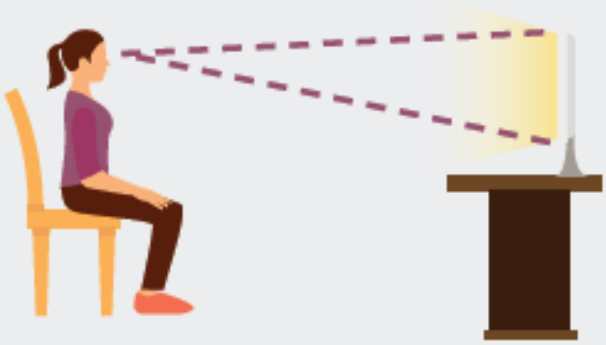
A hora das refeições

COMA DEVAGAR

Opte por realizar as refeições num ambiente calmo e com tempo. Demore o tempo que necessitar.

Opte por realizar as refeições sempre sentado corretamente (usar sempre cadeira e mesa e evitar comer no sofá, por exemplo);

Evite ver televisão ou outras distrações no momento da refeição. Caso opte por ver televisão, esta deve estar ao nível dos olhos para manter uma posição correta da cabeça e pescoço.



Opte por copos largos e baixos, evitando a má postura de cabeça e possíveis engasgamentos.

Como posso engolir melhor?

- Durante a mastigação, massaje com a ponta dos dedos as bochechas (para evitar que a comida fique acumulada na boca).
- Movimente a língua e as bochechas para juntar a comida com a saliva e garantir que engole tudo o que tem na boca.
- Engula com a cabeça ligeiramente inclinada para o peito.
- Quando colocar comida/bebida na boca, mantenha na boca por alguns segundos e só depois engula.

Obs

_____

_____

_____

A pessoa que ajuda na alimentação deverá:

Estar sentada ao mesmo nível da pessoa que irá alimentar.

Estar sentada frente-a-frente.

Aguardar que engula antes de dar mais alimento.

Mostrar o alimento que irá dar e explicar o que é.

Sinais de alerta

Mesmo a fazer uma alimentação adaptada podem surgir algumas complicações.

Se sentir, ou se alguém observar, os seguintes sinais antes, durante ou depois de comer ou beber, deve avisar os profissionais de saúde:

- Voz alterada, como se estivesse "molhada"
- Aumento das secreções e/ou alteração da cor (amarelada ou esverdeada)
- Tosse
- Falta de ar ou cansaço
- Pigarreio
- Sensação de corpo estranho na garganta
- Respiração ruidosa

Para cada pessoa a alimentação deve ser adaptada pelos especialistas em Nutrição e Terapia da Fala , em conjunto com os enfermeiros, médicos e terapeutas ocupacionais.

Todos somos responsáveis pelo sucesso na reabilitação!

Agora...

As mudanças na alimentação poderão ser difíceis e trazer dúvidas.
Este pequeno manual fornece algumas informações e indicações sobre como fazer essa mudança de modo mais fácil.
No entanto não susbtitui a ajuda dos profissionais que o têm acompanhado.

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Professora Doutora Margarida Figueiredo Braga
Faculdade de Medicina da Universidade do Porto

Appendix 5:

QUESTIONÁRIO SOCIODEMOGRÁFICO

Data	_____/_____/_____
Data de Nascimento	_____/_____/_____
Sexo	**Masculino** ☐ **Feminino** ☐
Escolaridade	Sabe ler e escrever ☐ Ensino primário ☐ Ensino secundário ☐ Curso Superior ☐
Com quem vive	Sozinho/a ☐ marido/esposa ☐ Filho/a ☐ Cuidador/a ☐ Pais ☐ Pai ☐ Mãe ☐ Irmão/ã ☐ Outro ☐ _____
Descrição do episódio clínico neurológico:	

Appendix 6:

Inquérito de Satisfação

Adaptado de ***Patients Satisfaction with the interview assessment questionnaire (PSIAQ)***
Delvaux et al. 2004

Caraterize, entre 1- nada satisfeito e 4- muito satisfeito, o **seu grau de satisfação** em relação aos profissionais de equipa (terapeutas, médicos e enfermeiros) em cada um dos seguintes itens, assinalando a opção que considerar mais adequada:

Item		1 – Nada Satisfeito	2 – Pouco Satisfeito	3 – Moderadamente Satisfeito	4 – Muito Satisfeito
7.	**A forma como os profissionais de saúde se apresentaram**	☐	☐	☐	☐
8.	**O modo como os profissionais de saúde me receberam**	☐	☐	☐	☐
9.	**Os esclarecimentos prestados pelos profissionais de saúde em relação ao meu problema em comer**	☐	☐	☐	☐
10.	**A capacidade do profissional de saúde para ouvir as minhas preocupações em relação ao meu problema alimentar**	☐	☐	☐	☐
11.	**A forma como os profissionais de saúde responderam às minhas dúvidas**	☐	☐	☐	☐
12.	**A capacidade dos profissionais de saúde para me tranquilizarem**	☐	☐	☐	☐
13.	**A disponibilidade apresentada pelos profissionais de saúde**	☐	☐	☐	☐
14.	**Globalmente, a forma como comunicou com a equipa**	☐	☐	☐	☐

Appendix 7:

Inquérito da informação/conhecimentos recebidos

Caraterize, entre 0- Não sei, 1- Não concordo e 2- Concordo, o **seu grau de concordância** em relação às afirmações em cada um dos seguintes itens, assinalando a opção que considerar mais adequada:

Item	0 – Não sei	1 – Não Concordo	2 – Concordo
1. Em relação ao meu problema de alimentação é claro para mim porque é que surgiu	☐	☐	☐
2. Sei que a disfagia é uma dificuldade em engolir causada pela minha doença.	☐	☐	☐
3. Sei o que posso comer sem me colocar em perigo	☐	☐	☐
4. Sei como devo preparar as minhas bebidas sem me colocar em perigo	☐	☐	☐
5. Sei que a minha dificuldade em engolir pode colocar em perigo a minha saúde, porque se não cumprir as indicações posso ficar com problemas em respirar	☐	☐	☐
6. Sei que a minha dificuldade em engolir influencia a minha saúde geral	☐	☐	☐
7. Sei que devo ter alguns cuidados onde faço as refeições e na forma como me sento à mesa	☐	☐	☐
8. Sei que há alguns sinais a que devo estar atento(a) quando como	☐	☐	☐
9. Se necessário, sei explicar como devem ser preparadas as minhas refeições	☐	☐	☐
10. Sei que posso fazer terapia para melhorar o que como e como o faço	☐	☐	☐